End of life care at Ballarat Health Services: Family members' perspectives

Jade Odgers

Manager

Grampians Regional Palliative Care Team

2013

Acknowledgements

I would like to express my sincere thanks to Dr Wendy Penney, Deputy Head of School Nursing, Midwifery and Healthcare, Federation University, Ballarat for her data analysis, support and direction given to me throughout this research. Also Denise Fitzpatrick, End of Life Framework Project Coordinator, Governance and Risk Management Unit, Ballarat Health Services for her passion for good end of life care in our organisation.

I thank those family members who took the time to speak with me about their journey. I appreciate that without their candour, experience and knowledge I would not have gained a better understanding of current end of life experiences or been able to ascertain some of the issues and needs of people dying in within Ballarat Health Services.

Jade Odgers

> How one dies remains in the memories of those who live on.
>
> Dame Cicely Saunders

Table of Contents

Abstract

This research explores the experience of family members in relation to the end-of-life care their loved ones received at Ballarat Health Services (BHS). Family members who had experienced the death of a relative at BHS were invited to participate. This research adopted a qualitative interpretative design, and data was collected via semi-structured open-ended individual interviews. The intent of the research was to explore the meaning of end of life care for family members. It is anticipated this research will inform the End-of-Life framework for BHS.

Twelve participants kindly shared their very private thoughts and memories of the death of their loved one at BHS.

Five key themes emerged following analysis of data.

- Conversations and Communication
- The family's' preparation for death
- Follow up after death
- The care experience
- The dying experience.

Health care professionals are uniquely positioned to play an integral role in not only supporting the person who is dying but also their family during end of life care. This care is a vital focus for health care professionals in the last days and hours of the person dying and their family. It is essential that health professionals in all settings are equipped to provide the highest possible standard of end of life care.

Carve your name on hearts, not tombstones. A legacy is etched into the minds of others and the stories they share about you.

Shannon L. Alder

Introduction

Often health care professionals involved with the person who is dying and their families struggle to determine if death is approaching and therefore battle to provide care in a structured and effective way. Health care professionals working in acute care settings understandably find it difficult to move from a life-preserving mode of work to the acceptance of dying, resulting in precious time being lost in supporting the patient and their family in doing the work of dying. It is hoped that this research will expose the experiences of the dying process with in Ballarat Health Services (BHS) from the family’s perspective. Knowledge from this work will inform the BHS End-of-Life Framework which will facilitate a more creative and life-affirming approach to the care of the person who is dying.

When will we become at ease with the fact that there are limits to medicine and that letting people die does not represent failure, that there are limits to human life? Caring for a person who is dying and their family can be one of the most rewarding aspects of our jobs. This can be a time of joy, dignity, sadness and, more importantly, peace. Most people who are dying are well aware that their death is imminent and welcome the opportunity to talk to members of the health care team about any concerns they may have. It is an absolute privilege and an honour to be a part of this very precious time in a family’s life.

The Proposal

This research explores family members’ experience of the end-of-life care (EoLC) that their loved one received at BHS. Family members who experienced the death of a relative were invited to participate in a semi-structured interview. Participants were recruited by a personal letter of invitation. Participants were asked to describe the EoLC their relative received, including any information about the dying process they may have been given by the health care team. Interviews were audio recorded, transcribed and analysed to identify common themes.

Background

Whilst researchers consider Australia to have some of the best palliative care services in the world, those researchers also remark that almost two thirds of people who die in Australia die in an acute hospital (Bloomer, Moss & Cross, 2011), not in a facility dedicated exclusively to the provision of palliative care. Of the people who have died in acute hospitals 70% received active treatment up until the moment of death, suggesting that health care professionals did not recognise that the person was dying (Hillman, 2009). Research such as this suggests that acute care focuses more on treatment and cure, and this reduces the opportunity for the person who is dying and their family to receive optimal EoLC (Aleksandric & Hanson, 2010). In the past three decades there have been many changes in the delivery of care and the experience of dying within acute care settings. There are increasing rates of chronic diseases resulting in longer periods between diagnosis and death. Patients and their families are better informed about the availability of services and support, which has resulted in more referrals to palliative care (Sharry, 2009). However, many families and their loved ones are still missing opportunities for optimal EoLC in the acute care setting.

It is the memory of how someone dies that will live on with those who are bereaved (Teno, Casey, Welch & Edgan-Levitan, 2001). The loss of a family member can have associated physical and mental health consequences and increase the mortality rate of the bereaved person. Throughout the dying process what was once important for both the family and their loved one may change. The definition of what is quality care may be different for each person (Ellershaw & Wilkinson, 2011). At the end of life it is the comfort of the person who is dying that is vital to all decisions about care and treatment, with goals of care adjusted as death approaches. It is essential for clinicians to consider the person who is dying and the family in this decision-making process. Health care professionals have a duty of care to ensure the wishes of the person who is dying and their family are met.

Bloomer et al. (2011) note it is important to differentiate between palliative care and EoLC, to ensure that health care teams understand the timing and intent of the care. Confusion often surrounds the terms used within the palliative care context. As palliative care can include a number of phases for people with a terminal illness, the wider community and health care professionals may often fail to make the distinction between the terms palliative and end stage or EoLC (Ellershaw & Wilkinson, 2011). Palliative care is applicable early in the course of an illness, but also includes care at the end of life and support for those who are bereaved. In practice, palliative care may be delivered to people with a range of conditions in a variety of health care settings (Milligan, 2012) and can be considered a holistic approach to care. In the acute setting, treatment is more goal-oriented, and can take priority over good EoLC.

Research suggests that at end of life there is a requirement for open communication with the person who is dying and their relatives or carers regarding death and the provision of consistent, up-to-date information by the treating team. The emphasis should be on communication, planning, symptom management and spiritual and psychosocial care as components of EoLC (Lunney, Lynn, Foley, Lipson & Guralnik, 2003). These key components impact significantly on the quality of care provided at the time of death. This should also occur further when a person is dying from an unexpected event or illness where little time passes between diagnosis and death (Bloomer et al., 2011).

Whilst Australia has some of the best palliative care services in the world, the reality is that almost two thirds of those who die in Australia die in an acute hospital and are potentially denied this world-class care. It is therefore essential that EoLC can be adequately provided across all health care settings. Health care professionals must have the knowledge, skills, attitudes and behaviours to provide an integrated and person-centred approach to care at end of life.

Methodology - Interpretive Intent

In choosing a qualitative mode of inquiry for this research the decision was made not to adopt a set traditional approach. Based on the purpose of exploring family members experience of EoLC an interpretive design was identified as the methodology best suited for this preliminary study.   Interpretive research is research with the intent to understand and allows the researcher to gain knowledge about participants' experiences. This research approach also considers the researcher's own experiences and this shapes what is learned. In conducting this research it was imperative that I acknowledged my knowledge and experience as manager of a palliative care service while being open to learning from the participants. The aim of interpretive approaches to research is to describe, explore and create meaning from a social or practice setting. For the interpretative researcher reality is not fixed and depends on the events and experiences that are explored (Schneider, Whitehead, Elliott, LoBiondo-Wood & Haber, 2007).

Interpretive research is considered to be a post-positivist approach to research which suggests that the researcher is not value free but that he/she is affected by social, cultural and political points of view (Schneider et al, 2013).This approach determines that the researcher is not restricted by the limitations of traditional research and therefore the distance between the researcher and the participants is minimised. According to Grant and Giddings (2002) interpretive research focuses on an individual's actions or experiences and their explanation of them. Both the researcher and the participant are involved in data collection, the participant by sharing their experience, and the researcher by interpreting and analysing this material.

The basis of interpretative research is to identify themes and patterns from the perspective of the participant. Nursing in particular has found this type of inquiry particularly useful as it moves "beyond established qualitative methodologies in order to generate credible and meaningful disciplinary knowledge" (Thorne, Kirkham & O'Flynn-Magee, 2004, pp. 3). Interpretative researchers in nursing are not satisfied with description only and look for meanings and explanations within the data that may lead to clinical application.

An interpretive research methodology was chosen for this research because the aim was to explore how the participants made sense of the experience of their loved one dying in the acute setting. A critical aspect of interpretative research is listening and observing, with data collection through the use of interviews. This methodology is also useful when previous research has been limited (Adams, 2010). A review of the literature demonstrated very little research had been undertaken on EoLC in the acute care setting; however, there had been research undertaken in palliative care, aged care and intensive care settings.

Using Semi-Structured Interviews

Interviews provide the researcher with an opportunity to see the world through the participant's eyes and to reflect on the participant's experience. Semi-structured interviews provide a set of questions that ensure the aims of the research are achieved. However, there is also an opportunity to ask additional questions to probe or clarify (Schneider et al., 2013). The questions help the researcher navigate the interview but there should be enough flexibility to ask other questions in order to pursue other leads or seek clarity (Schneider et al., 2007).

The strength of using semi-structured interviews is the flexibility it provides to follow a number of predetermined questions but also to explore other issues as they are raised by the participant (Ryan, Coughlan & Cronin, 2009). Semi-structured interviews are conducted like a conversation where the researcher is actively involved, encouraging the participant to talk and be engaged in the topic being researched. This requires skill and experience on behalf of the researcher and because of this it is often the researcher and not the research assistant that undertakes the interviews (Rice & Ezzy., 2001). In conducting the interviews in this way I was able to explore participants experience taking into consideration their individual relationship with their loved one and the circumstances in which death occurred.

It was expected the interviews would take between 45 minutes to one hour to complete. Interviews were conducted by face to face meetings at a location agreed upon by both the participant and researcher. On average the interviews lasted just over 35 minutes, although one interview lasted over an hour and half. Each interview was audio recorded and participants were informed that they could request that the recorder be turned off at any time. Pseudonyms have been provided for all participants, family members and health care professionals for the purpose of confidentiality.

Rigour and Reflexivity

Rigour in qualitative research is determined by openness, adherence to a philosophical perspective and comprehensive data collection. Rigour is also defined by the method of data analysis and the researcher's self-understanding. This self-knowledge ensures the researcher has insight into their biases. As stated by Grove, Burns, Gray (2013) it is these characteristics that are paramount to produce valid research. Seminal work by Sandelowski (1993) argues that the strengths of qualitative research such as artfulness, versatility and the human experience afford the best test of rigour in qualitative research.

Methodological rigour in this research has been demonstrated by utilising the methods described by Rice and Ezzy (2001). Documenting participants' recruitment, engagement and how rapport was developed assisted in establishing rigour. Rigour is also demonstrated by the way in which the interviews were recorded and transcribed, and data analysis was clearly and concisely documented. Dr Wendy Penney also completed an independent thematic analysis of the data and results were compared to the original analysis. The validity of the interpretations of the data is supported with the use of excerpts and direct quotes from the participants.

Thematic Analysis

Thematic analysis concentrates on individual themes and patterns of behaviour. It identifies what and how often a concept or theme emerges in a text, focusing on identifiable themes. The process of data analysis in this research started with interviews being taped and transcribed verbatim. Each transcript was audited against the original audio tape by carefully listening, reading and rereading the transcript. This process, though time consuming, not only allowed me to become familiar with the data but enabled me as the reader to evaluate the research in terms of rigour as it provided an audit trail (Rasmussen, Muir-Cochrane, Henderson, 2012). The transcribed interviews and the recordings were stored on a password-protected computer.

To undertake the thematic analysis each interview was transcribed, reread in full and then the audio recording was replayed for accuracy. All of the interviews were coded to de-identify the participant. Potential themes were identified by grouping data and then returning to the original transcripts and audio recordings to ensure the correct meaning of the themes had been interpreted and that none had been overlooked. The themes were then defined with clear descriptions and the supporting data from the transcriptions. From this process five key themes were identified and defined (see Table 1). These themes are further explored in this report.

Table 1

Theme	**Definition**
Conversations and Communication	This included discussions or communication with nurses and medical staff on the current health status of their loved one. This may have included formal family conferences or bedside conversations.
The family's' preparation for death	Conversations with nurses and medical staff about the dying process. This may also include conversations between family members and their loved one.
Follow-up after death	Conversations, meetings or any contact from the health care service after the death of the participant's loved one.
The care experience	The care received by their loved and themselves by members of the health care team
The dying experience	This is the description of the death, whether the participant was present or not. It included the viewing of the body on the ward.

Ethical Considerations

Prior to the initiation of recruitment of participants or data collection, permission to undertake this research was obtained from the Ballarat Health Services and St John of God Ethics Committee.

Informed Consent

Additional precautions were undertaken to ensure that participants understood they could withdraw from the research at any time without consequence. A plain language statement and an informed consent form were mailed to participants at least one week prior to their interview. The process of obtaining informed consent was reviewed at the beginning of each interview to ensure that each participant understood the process.

Vulnerable Participant Group

It was identified that this participant group may be vulnerable and so a great deal of consideration was given to the possibility of further distressing participants who had recently lost a loved one. It was essential that the benefit of participating in the interview outweighed the burden engendered by the interview process, and that any negative outcomes incurred by the participants were minimal.

Participants and Recruitment

A total of 15 participants were recruited for this research, however only 12 interviews were conducted. The participants were the family members of a person who had died on an acute ward. For the purpose of this research, “family member” was defined as a relative or close friend of a person who was dying and who was in attendance during the last days of that person’s life. Exclusion criteria for the research included patients under 18 years of age, family members under the age of 18, family members who did not speak English or relatives of a patient who died in an acute ward outside BHS.

The Themes

Five key themes emerged following interviews and analysis of data. The first theme was conversations and communication during the final admission to hospital. The second theme was planning for death and the participant’s awareness of their loved one’s wishes. The third theme considers follow-up and bereavement support from the health service. The fourth theme was the care received by the participant and their loved by the health care team. The dying experience was the fifth theme to emerge. These themes emerged as a result of broad questions that were asked during the interview process.

The themes will be explored using examples from the interviews to demonstrate significance and relevance.

Conversations and Communication

As discussed by Frank (2009) the theory of a “good death” is based on good communication skills that facilitate the sharing of timely and accurate information, thus encouraging the person dying to participate in end of life decision making. Frank’s literature review demonstrates that there is clearly a role for nurses during end of life decision making. When a person who is dying and their family are actively involved in end of life decision making it encourages positive relationships to be formed between the family, their loved one and nursing staff

Conversations and communication with the health care team emerged as a theme from the interviews. According to the participants, the degree and quality of the communication about their loved one’s wishes and care needs was variable. Some interactions took place in the form of a formal family meeting while for other participants, communication was informal, involving, for example, bedside or corridor conversations. Positive examples of communication are as follows:

> *Peta: They said “He’s had such massive damage to his heart that he’ll be severely invalided forever.” They sort of said, you know, “It’s up to you, you tell us what you want to do, but you need to be aware that he’s going to be severely invalided.”*
>
> *Pam: Your father’s back in hospital because his breathing’s not good, and his cough, and he’s not coping.” He said, “I’ve had a discussion with your father, he said I’ve had it before, he wants no more treatment. He said doesn’t want anything or he’s finished with it.” I said, “Okay.” …we respected dad’s wishes*.

Some of the conversations with family were inferred or the care that was provided inferred that death was approaching

> *Mary: I thought, “They sound like they’re letting me know gently that the end is in sight.” So it wasn’t a big surprise*
>
> *Anne Marie: …so I met my brother at the hospital at 10.00 am. As I got there they were moving him into a single room. I know what that means.*

One family had very little communication with staff and therefore was shocked when particular interventions were removed without discussion with any of the patient's family members:

> *Jodie: … we just guessed…with everything disconnected, like Saturday he was connected to glucose or some clear glucose stuff and he had oxygen and yet when we got there Sunday morning he was connected to nothing.*
>
> *Julie: The nurse who kept spraying the perfume said to us in the corridor one time, "We don't know, it could be three days, three weeks, we don't know." Which is crap. It's crap. My daughter said, "Mum, we know."*

In an article by Hayes (2010), effective communication skills are considered a key point to providing high quality EoLC. Nurses should be able to recognise that death is approaching and be prepared to have discussions with the family about future care needs. According to Hayes (2010), training in communication would increase the confidence of nurses to engage in these difficult conversations.

The family's' preparation for death

The second theme that was identified was the family's' preparation for death, which included funeral and advance care planning. In acute care settings there is a focus and expectation of cure. Death can be seen as a failure of the health care system and this can contribute to health care professionals' anxiety about talking to patients and their families about death and dying (Al-Qurainy, Collis & Feuer, 2009). Good communication in identifying, responding to and meeting the needs of both family and patient, with the emphasis on care with dignity, can be beneficial (Talking about end of life care, National End of Life Care Programme, 2011). Impending death can be difficult to discuss with families but quality care depends on health care professionals being able to talk about it. Effective communication requires the right conversations by staff with the right skills taking place at the right time (Talking about end of life care, National End of Life Care Programme, 2011).

Some of the families interviewed prepared for death well and were aware of their loved one's wishes**.**

> *Peta: So it kind of didn't surprise us that, well it didn't surprise me anyway that he said, "Okay, no more treatment." What surprised me was that people agreed to it.*

> *Bernie: When the time came it was so easy, because again, I knew what he wanted. And didn't have to think, oh would he like this?*

For other family members there was very little preparation for their loved ones impending death at BHS

> *Jill: … they said, you know, "What do you think he would want?" My sister said "It's really hard to choose for someone else, when you're ending their life*

For some family and their loved one the opportunity to die at home was discussed but the opportunities were never availed to them

> *Kerrie: I first heard news that the doctor there thought that he would die in hospital within weeks. I said, "Well, I'd like to take my grandfather home." That was completely dismissed by that doctor and in an arrogant way too. He basically said, "I'm not going to talk about that at this point."*
>
> *Mary: …During our discussions with hospice at one point in time, close to around about that stage, the social worker at the time said to us, "How do you feel, what do you want?" Anne needs to know what you want. And he said, "Oh, I want to be at home."*
>
> *Trish: …Yeah, the most hurtful part was when I was told, when that doctor said to us, that he would be dead within a couple of weeks and I said about taking him home and that's my biggest regret, that I didn't take him home.*

The term advance care planning is widely used in the health system. I assumed that this term was used with patients and their loved ones by the health care team. However, there appeared to be confusion for families about advance care planning as opposed to funeral planning. Health care services widely use advance care planning documentation, and programs such as "Respecting Patient Choices" are embedded into their policies. However, for this participant group this terminology was foreign. Participants were eager to explain that they knew what their loved one wanted for funeral planning but they were unaware that they may have missed out on the opportunity to discuss their loved one's end of life care

Follow-up after death

A literature review undertaken by Fauri, Ettner and Kovacs (2000) identified that little research on acute care bereavement services had been undertaken. Although the effects of long-term grief issues can manifest itself in physical and emotional distress and may lead to mortality, there is little evidence to suggest that acute care services offer any formal bereavement services. Services should address immediate needs of the family but also provide services that are preventative in nature. Staff can also benefit from these services knowing that the family is being emotionally cared for by the health service. For many years palliative care services have recognised the importance and benefits of providing bereavement services and this is considered to be part of the continuum of care (Fauri et al., 2000).

There was mixed messages from the participants about follow up from BHS in terms of making contact with them after their loved one died

> *Mary: Probably I think, perhaps that follow-up phone call, particularly considering the circumstances around Peter's death. I felt that perhaps that could have been explained to me a little bit better*
>
> *Pat: They said to me, "Someone will give you a call tomorrow" and I never heard a thing from anyone until I wrote to them and I got a letter back from them saying they would have rung me if he'd have asked*
>
> *Sharon: While he was there they did what they could. It was always going to have this outcome I think, looking back. He was peaceful. The room was, you know, he was in a quiet room, we had lots of time with him. Yeah, I didn't expect to hear back from the hospital*
>
> *Julie: …I don't know. I don't know what the normal procedure would be. I think probably I was a little disappointed that the hospital in no way actually followed up, social worker or anybody.*

It appears that if an adverse event occurred during that final admission the participants would have like a follow up call from someone from the hospital. The other comments about follow up referred to when the patient had been a long term user of our health service ie. Oncology.

> *Julie: I would've, like I know they're really busy because those ladies in Oncology, see I still haven't been back, I can't. But the ladies in Oncology, they were G's life. He just loved them, more than he loved me I think*.
>
> *Kim: I don't know what the process is but it just does seem like he's died and that's the end of the story. I think it would give a nice personal touch and that you're not just a number*

For some of the participants they were at bereavement risk and referrals were made to the appropriate supports after the interviews took place.

> *Kim: I actually ended up having a breakdown after Pop's death. So, it's been a pretty long road*

. *Sharon: You've looked after them for years and years and years and then all of a sudden they're gone. It's like someone closing the door and it's bang. There's nothing behind it. You're on your own*.

Sharon: I just want to end everything. So you are having suicidal thoughts? *Yeah, I did*

Street, Love and Blackford (2004) compared the attitudes of health care professionals to bereavement across three settings: palliative care, aged care and acute care. They reported that in the acute setting there were competing demands where the nursing focus was on curative care, respite and rehabilitation, and that as a result bereavement support was not addressed. Support for the family did occur during the dying process but did not continue after death. Interestingly the study showed that when a patient was labelled "palliative care" their family may have received follow-up. However, according to Street et al. (2004), if a person was labelled "medical" and died the family received no follow-up. The physical resources available for bereavement support for families is limited in the acute setting and so when death does occur in this setting it is dealt with by existing resources. This may not be sufficient to meet the needs of grieving families.

The caring experience

The care received from members of the health care team varied in quality. For some participants it was very clear that they believe their loved one received "good" care.

> *Myra: So, but I couldn't speak highly enough of what - I haven't got anything negative to say about what they did at the Base. Nothing negative… they were really good, very good…They were just wonderful to her. Absolutely wonderful. Kept her comfortable at all times.*
>
> *Jacinta: The nursing staff were exceptional. They were very attentive, they were very, there were quite a lot of very good nurses caring for him, the medical team, the oncology department, I couldn't speak highly enough of. It was wonderful*
>
> *Sharon: The staff were brilliant. They explained things that they were doing for dad. They'd come in and say, "Okay, we're just checking out this or that*

However there was physical care that was unacceptable and will be the memories that family will continue to have of their experience at BHS. This is supported by the following comments:

> *Meg: She buzzed and buzzed to go to the toilet. Our younger brother, he said, she ended up pooing her bed. He buzzed them. He could hear them talking. He ended up going up to them and saying, "Get up there and clean up my mum."…. You don't want anyone to be incontinent. And they were telling her to 'do it in the bed.'*

> *Meg: … others would just chuck her tablets on the table and walk out. Sometimes we'd ask if they could break them in half or quarters and they looked annoyed to have to do that, but mum couldn't swallow because of her Parkinsons*
>
> *Sharon: At this stage he wasn't getting out of bed and there were a couple of nurses I think that made it difficult for him on the ward, who didn't believe that he couldn't walk.*

The emotional care of the participant and their loved one was not always a key priority of staff at BHS and once again we have impacted on the participants memory of how their loved one died

> *Meg: She never wanted us to complain. I don't know whether she got afraid that if we complained that they might be nasty to her. I would go to see her every morning and every night and she would say, "Geraldine, we're old. They don't care about us anymore."*
>
> *Julie: The thing is we're all human beings. You're still a human being until the day that you take your last breath. Mum was still a human being at the age of 81. A lot of that care was just not right. She even knew that herself. You don't have to be told to "Do it in bed" rather than going to the toilet*
>
> *Pat: I just think to myself*, "You guys, you're going to be there yourself one day." When someone doesn't treat you with dignity. Dignity is gone, especially when you're in a shared room …. The dignity just isn't there
>
> *Meg: That woman in ED, I couldn't believe it. She nearly tackled us to the ground. Like we were in a rugby team. We've just been told mum is dying and we're going out to see her and she said, "Two at a time.*"

The question is are we caring for our patients as health care professional to patient or can we care for our patients as human beings? Can we not provide more flexible care the meets the needs of the family and the patient?

The dying experience

The actual death of a participant's loved one was identified as a theme. Some participants were present when their loved one was dying and then eventually died. Other participants had chosen not to be present and were comfortable with this decision. However, others were distressed and disappointed that they were not present at the actual moment of death. For some of the participants they described a sudden event or traumatic death.

> *Julie: So we've just gone in thinking they've either shut it [the curtain] to give him a wash and as I've pulled it back I've just gone, "Oh my God, what's wrong with Graeme?" My daughter said, "Mum, he's gone."*

> *Jac: I think probably the other thing that quietly sat in my mind through that shock was the information given to me on the phone when the doctor rang me to tell me that Paul had passed away, was that they had commenced resuscitation but then became aware of a NFR order that was in place and they ceased immediately.*
>
> *Betty: I had about fifteen minutes with him. I was really cheesed off with the hospital that they didn't ring me and tell me how desperately ill he was,*

Families can feel neglected in the absence of timely, regular communication from the health care team. An honest open conversation about the dying process and the signs of dying can inform family of what to look for.

For one participant she was able to describe a good death and was grateful for the experience. This family had overt conversations with the health care team and were obviously aware that death was approaching

> *Sharon: …but that was really his last cognisant evening and we all stayed at the hospital with our partners and we just sort of sat round the bed and he had a lovely time. He chatted, I mean his words were a bit slurred sometimes or he'd forget words. …. He just had a lovely time that last night.*

Most participants expressed that they knew, and their family knew, that their loved one was dying. However, the open, honest and candid conversations with the person who was dying or their family that death was approaching did not occur with the health care team. Hardy (2005) states that many people who are dying and their families can remain unaware of the terminal prognosis even when death is anticipated by the treating team. As family members were usually present in the acute hospital, and some were actively involved in care, there were many opportunities for the health care team to discuss the dying process with the person who was dying and their family

Conclusion and Recommendations

The Challenges of Dying at Ballarat Health Services

We live in a world where death is seen as a failure of the medical system, and in a medicalised health care system the concept of a "good death" can be difficult to conceive. There needs to be a balance between the technical/medical interventions and the humanistic approach to care. Learning to talk to a dying person and their family can be difficult and takes training, time and practise. It is acknowledged that it can be difficult to tailor care when the goals of care have changed. This requires a workforce that easily adapts to change and can effectively communicate the new goals of care to both the patient and family (Al-Qurainy et al., 2009).

Communication

All but one participant identified communication between the family and health care professionals as an issue, current research supports the contention that effective communication contributes to people experiencing a good death in an acute hospital setting. A factor impacting on communication is the delay in EoLC decision making when there is a strong focus on goal-oriented care as opposed to holistic care in the acute care setting. The quality of the communication with family impacts on the perceived quality of the death.

Effective communication skills are considered a key to providing high quality EoLC. Health care professionals should be able to recognise that death is approaching and be ready to have discussions with the family about future care needs (Hayes, 2010). Training in communication can increase the confidence in health care professionals to engage in these difficult conversations.

Research suggests that health care professionals can be taught communication skills and these skills can be refined with practise. This can promote an environment in which they can elicit and respond to the emotional cues of both the patient and the family (Victorian Cancer Clinicians Communication Program, 2008). Research highlights the importance of recognising that all staff who work with people who are dying are properly trained to look after dying patients and their families.

Recommendation One: There is recognition that all staff who work in acute care settings are properly trained to care for people who are dying and their families. Ongoing education and training should also focus on improving communication skills, including learning appropriate responses to emotional cues and having difficult conversations.

Advance Care Planning

Conflicts sometimes occur between the wishes of the person who is dying, their family, and recommendations from the medical specialist. Advance care planning can involve a living will or the appointment of a medical power of attorney. A medical power of attorney gives a named person the legal authorisation to direct care on behalf of the patient. According to Basile a “good death” can be achieved when planning is combined with “ethical care”.

The term advance care planning was foreign to all the participants in this research. Although this term is widely accepted within the health setting and its intention is clear, it should be acknowledged that it is not a term commonly used or understood by patients and their families.

Recommendation Two: It is recommended that a formal program of advance care planning is adopted by BHS and integrated into primary care services. This would ensure that community based clients who are admitted to BHS have advance care directives already documented prior to admission.

End of Life Care Pathways

End of Life Care (EoLC) pathways provide a supportive tool for use in services that have limited access to palliative care specialists, and for services seeking to provide a standardised tool to aid decision making by less experienced practitioners (Hardy 2005; Chan & Webster 2011; Ellershaw & Wilkinson, 2011; Veerbeek, Van Zuylen & Gambles, 2006; Department of Health, 2011). In this respect EoLC pathways, with the guidance they provide on what should be done to support the dying person and when this support should be implemented, offer a positive step towards better management of people at end of life (Le & Watt, 2010; Department of Health, 2011). The National Palliative Care Strategy (2010) recommends that action be taken to support the national roll-out of an integrated care pathway across primary, acute and aged care settings. This includes incorporating specific references to palliative care and the end of life stages in all relevant national and state plans, frameworks and clinical guideline documents.

Recommendation Three: A structured approach to EoLC such as a pathway or care plan is part of the solution to improving the experience of people dying on all wards within BHS

Conclusion

Palliative care and EoLC is not the domain of only specialist staff or specialist services. EoLC is a vital focus in the last days and hours of the dying person and their family/carers. Therefore it is essential that health professionals in all settings are equipped to provide the highest possible standard of care at that time. In 2009, the Department of Health suggested that palliative care had shifted in response to the fact that people are living longer with life-threatening illnesses. It noted the importance of all health care professionals in ensuring that symptom control and improving quality of life remain a focus until death.

Care of the dying person and their families at end of life can have an impact on the emotional, physical and spiritual well-being of those left behind. If we can find ways to improve care we can have a positive impact on the memories of those left behind. I acknowledge that this research is based on a small sample group and may not reflect the experience of all family members who experienced the death of a loved one in BHS. There has been little research in this area but the themes identified are consistent with the limited research available. I also acknowledge that more research needs to be conducted to further explore this important topic. The goal is to improve outcomes for the increasing numbers of people who die at BHS on our acute wards and for their families.

Reference List

Adams, E. (2010). The joys and challenges of semi-structured interviewing*. Community Practitioner, 83* (E7), 18-21.

Aleksandric, V. & Hanson, S. (2010). *Health system reform and care at end of life: A guidance document.* Palliative Care Australia, Deakin West, Australia.

Al-Qurainy, R., Collis, E., & Feuer, D. (2009). Dying in an acute hospital setting: The challenges and solutions. *International Journal of Clinical Practice, 63* (3), 508-515..

Bloomer, M., Moss, C., & Cross, W. (2011a). End-of-life care in acute hospitals: An integrative literature review. *Blackwell Publishing Ltd,* 1-9.

Bloomer, M., Moss, C., & Cross, W. (2011b). Problems associated with care at end of life in acute hospitals. *End of Life Journal, 1,* 1, 1-7..

Chan, R., & Webster, J. (2011). A Cochrane review on the effects of end-of-life care pathways: Do they improve patient outcomes? *The Australian Journal of Cancer Nursing, 12* (2), 26-30.

Department of Health (August, 2011). Strengthening palliative care: Policy and strategic directions 2011-2015, State Government of Victoria, Australia.

Ellershaw, J. (Editor), & Wilkinson, S. (Editor) (2011). *Care of the dying – A pathway to excellence.* New York, USA, Oxford University Press.

Fauri, D., Ettner, B., & Kovacs, P. (2000). Bereavement services in acute care settings. *Death Studies, 24*, 51-64.

Frank, R. (2009). Shared decision making and its role in end of life care. *British Journal of Nursing, 18* (10), 612-618.

Grant, B., & Giddings, L. (2002). Making sense of methodologies: a paradigm framework. *Contemporary Nurse, 13* (1), 10-28.

Grove, S., Burns, N., & Gray, J. (2013). *The practice of nursing research: Appraisal, synthesis, and generation of evidence*, *7th Ed;* Missouri, USA, Elsevier Saunders.

Hardy, J. (2005). *The Australian Best Care of the Dying Project (ABCD): Phase One Report:* 1-18.

Hayes, A. (2010). How nurses working in acute care can help to ensure patients achieve a good death. *Nursing Times, 106* (27), 18..

Hillman, K. (2009). *Vital Signs: Stories from intensive care*. Sydney, Australia, University of New South Wales Press.

Le, B., Watt, J. (2010). Care of the dying in Australia's busiest hospital: Benefits of palliative care consultation and methods to enhance access. *Journal of Palliative Medicine*, *13* (7), 855-860.

Lunney, J., Lynn, J., Foley, D., Lipson, S., & Guralnik, J. (2003). Patterns of functional decline at the end of life. *Journal of the American Medical Association, 289,* 18: 2387-92.

Milligan, S. (2012). Optimising palliative and end of life care in hospital. *Nursing Standard, 26* (41), 48-56.

National Palliative Care Strategy, (2010). Commonwealth of Australia.

Rasmussen, P., Muir-Cochrane, E., & Henderson, A. (2012). Document analysis using an aggregative and iterative process. *International Journal of Evidence-Based Healthcare, 10*, 142-145.

Rice, P., & Ezzy, D. (2001). *Qualitative Research Methods*, Melbourne, Victoria, Australia, Oxford University Press.

Ryan, F., Coughlan, M., & Cronin, P. (2009). Interviewing in qualitative research: The one-to-one interview. *International Journal of Therapy and Rehabilitation, 16*, No 6, 309-314.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science, December*, 1-8.

Schneider, Z., Whitehead, D., Elliott, D., LoBiondo-Wood, G., & Haber, J. (2007). *Nursing and midwifery research: Methods and appraisal for evidence based practice, 3rd Ed;* Chatswood, NSW, Australia, Mosby Elsevier.

Schneider, Z., Whitehead, D., LoBiondo-Wood, G., & Haber, J. (2013). *Nursing and midwifery research: Methods and appraisal for evidence based practice, 4th Ed;* Chatswood, NSW, Australia, Mosby Elsevier.

Sharry, C. (2009). Liverpool Project Final Report from the Grampians Regional Palliative Care Team to the Grampians Integrated Cancer Service and Grampians Region Palliative Care Consortium, Ballarat, Victoria, Australia, Unpublished.

Street, A., Love, A., & Blackford, J. (2004). Exploring bereavement care in inpatient settings. *Clinical Nurse, 17* (3), 240-250.

Talking about end of life care, National End of Life Care Programme, 2011.

Teno, J., Casey, V., Welch, L., & Edgan-Levitan, S. (2001). Patient-focused, family centered end of life medical care: Views of the guidelines and bereaved family members. *Journal of Pain and Symptom Management, 22* (3), 738-750.

Thorne, S. E., Kirkham, S., & O'Flynn-Magee (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods, 3* (1), 1-21.

Veerbeek, L., Van Zuylen, L., & Gambles, M. (2006). Audit of the Liverpool Care Pathway for the Dying Patient in a Dutch cancer hospital. *Journal of Palliative Care, 22* (4), 305-308.

Victorian Cancer Clinicians Communication Program, 2008, Victorian Cancer Council.